

# HEP C U Later

*"C Positive? Be Positive"*

A resource to assist the successful elimination of Hepatitis C

## Contents

Glossary	Page 2
Introduction	Page 3
Needle Exchange	Page 4
Assessment	Page 6
Care planning, keyworking and reviews	Page 8
Partnership working	Page 10
Treatment	Page 13
Data	Page 15

At the end of some of the chapters there will be a paper-clip icon in the possible solutions box, clicking on these will take you to a document of use for those possible solutions.

## Glossary

APA-	Addiction Provider Alliance
BBV -	Blood-Borne Virus
DAA -	Direct Acting Antiviral
DBST -	Dried Blood Spot Testing
DPIA -	Data Privacy Impact Assessment
DTS -	Drug Treatment Services
HBV -	Hepatitis B
HCV -	Hepatitis C
HIV -	Human Immunodeficiency Virus
ICS -	Integrated Care System
ODN -	Operational Delivery Network
OST -	Opioid Substitute Treatment
NDTMS -	National Drug Treatment Monitoring System
NHSE -	NHS England
NSP -	Needle and Syringe Exchange Programmes
PHE -	Public Health England
PIL -	Patient Information Leaflets
PCR -	Polymerase Chain Reaction
PWID -	People Who Inject Drugs
RNA -	Ribonucleic Acid
SOP -	Standard Operating Procedure

## *Introduction*

This document is about explaining what is possible – what we need to do to achieve our mission of eliminating hepatitis C in NHS APA drug and alcohol treatment services. It is a guide to support NHS providers in understanding what evidence and experience tells us is required and also to support and provide challenge with regards to how services are provided, organised and ultimately achieve this ambition. Each setting will have its own twist on how they proceed but the fundamental principles of increasing access, providing testing, engaging and maintaining treatment through to recovery remain consistent. The examples provided throughout illustrate the excellent practice that is already in place across many NHS providers.

It is on this basis that the Hep C U Later Programme exists – that is to enable collaboration across providers sharing the best of each trust so that overall across England we make a major contribution to the elimination of hep C and, as discussed at our recent 2021 ‘Vision Event’, change people’s lives for the better. With the ongoing impact and recovery from Covid 19 the need to restore testing for hep C across NHS services drug and alcohol treatment services is vitally important so we make up the ground lost in the last year – as of March 2021 testing rates are at approximately third of pre-pandemic levels. The Hep C U Later team stand square behind all of you in this mission and hope this document is one further aid to support you in this work.

We hope you find it helpful – please ask questions, provide any other examples of best practice you have and enable the Hep C U Later team to provide any support you require.

*Danny Hames*

Strategic Lead – Hep C U Later Programme and NHS APA Chair  
July 2021

### **Issue**

Needle and syringe exchange programmes (NSPs) have been part of drug treatment services (DTS) for decades. The main aim of NSPs is to reduce the transmission of blood-borne viruses (BBVs) and other infections (such as bacterial ones) caused by sharing injecting equipment, including hepatitis B (HBV), human immunodeficiency virus (HIV), and hepatitis C (HCV). Historically NSPs have been an accessible low-threshold service, and the 'front window' of the wider DTS. Amongst other things people have been able to get advice on minimising the harms caused by drugs; help to stop using drugs by providing access to drug treatment such as opioid substitution therapy (OST); and access to other health and welfare services.

HCV remains the most common BBV infection among people who inject drugs (PWID), and there are significant levels of transmission among this group in England and the UK. In 2019 in England, just over half (54%) of PWID tested positive for HCV antibody, and just less than one quarter (23%) had evidence of current infection. Many of these people were using NSPs before the pandemic hit, although they may be doing so less now.

At the same time, the increasing availability of new direct acting antiviral (DAA) drugs provides an opportunity to reduce morbidity and mortality from HCV, and to decrease the risk of onward transmission. The new DAAs are extremely effective, have a relatively short length of required treatment, and have almost no side effects.

NICE recommends that NSPs should offer (or help people to access) testing and treatment for BBVs including HCV. However, resourcing for NSPs has been under considerable strain over the last decade in terms of reduced resourcing and reduced capacity. The importance of prevention and harm reduction has begun to be re-emphasised at a national level of late in policy documents and discussions. This, combined with a modest recent re-injection of money into the system, means that there may be opportunities to review and rebalance local NSPs.



## Possible solutions



- Service/job/role review
- Procurement for DBST deployment in NSP
- Testing protocols
- Semi-structured conversational frameworks
- Bespoke recording systems

## Questions for NSP providers

- Does your needle exchange have the correctly resourced number of dedicated staff roles; and if so, what are these?
- Do staff have access to dried blood-spot testing (DBST) kit; and if so, which kind?
- Is there a protocol for systematically raising HCV testing with NSP users?
- Does engagement training for staff encompass motivational interviewing approaches?
- How does testing link with referral to treatment in your service or locality?
- Is there a recording system with power to link to the structured treatment record (if there is one) to flag testing status?
- Has NSP capacity been reviewed at a senior level in the last two years?

## Issue

Assessment is a critical point in the journey of the person entering treatment. People who inject drugs (PWID) are at much higher risk of death than other people with similar demographics who do not inject. They are at risk of drug-related death but they are also at increased risk of death through liver disease brought about by untreated hepatitis C (HCV) infection. Consequently the offer of not just opioid substitute treatment (OST) but also direct-acting anti-viral medication for HCV can be potentially - literally - life-saving. Assessment is, for most people, the first meaningful contact they have with a service, and it is an opportunity for the service to begin the process of engagement well.

Pragmatically, services need to strike a balance at assessment. On the one hand, the volumes of referrals to an assessment team (or the team delivering assessments) may be high, and behind the direct face-to-face work of an assessment there is a large amount of case recording and bureaucracy for the modern Practitioner.

On the other hand, there is a need for relative comprehensiveness, and there is also the potential for interventions (not just advice and brief interventions) to begin to be delivered there and then. People who are entering the service in the hope of receiving OST often have to wait another period of time after generic assessment before they see a prescriber and can start on medication. However, by prioritising something that can be delivered right now - a HCV test - the service can begin immediately to demonstrate its commitment to quality of care, one of the fundamental principles of the NHS. That in turn will generate trust and engagement between service provider and service user.



## Questions for NSP for assessment teams or teams delivering assessments

- Do staff have access to dried blood-spot testing (DBST) kit in the assessment setting?
- Has sufficient time been allocated to discuss and undertake a test?
- Have staff been trained in how to undertake pre and post-test discussions?
- Are there service guidelines to support those discussions and do they adhere to national guidance?
- Do these guidelines cover amongst other things consent (for testing, communication with GPs, referral to treatment services); how the test will be undertaken and results given?
- Are there patient information leaflets (PILs) which describe the above including treatment options including access and referral?

### Possible solutions



- Guidelines for pre and post-test discussion for Hepatitis B, C and HIV testing (see resources)

### **Issue**

A key principle is that everyone entering drug and alcohol treatment should be offered testing and, if required, treatment for hepatitis C (HCV). Recent years have seen a stronger focus on key working and care planning as a method for integrating the different elements of treatment and recovery-promoting interventions. The building of trust, through the demonstration of commitment to quality of care, which has begun at assessment, is supported by key working and care planning. The 'encounter' between keyworker/practitioner and service user is therefore the ideal place where this principle can be met.

The work of the keyworker/Practitioner normally involves regular meetings and/or reviews. In the main, interaction with a service user is pre-planned. However, sometimes - particularly so prior to the Covid pandemic - they occur opportunistically because the service user attends without an appointment. These meetings are opportunities to ask the service user about their recent possible risk behaviours, overall health, and any changed need that they might have to be screened for blood borne viruses (BBVs) to which they may have been recently exposed. This is part of a dynamic risk assessment process.

Testing for the presence of HCV, including polymerase chain reaction (PCR) testing for the presence of HCV RNA (and HIV, and hepatitis B infection) is clearly an intervention which can - and should - be carried out in this therapeutic 'space'. Some tests, oral ones, only show the presence of antibodies. They cannot diagnose whether the HCV virus has been cleared, or rather, if it is actively infectious. For the latter, a dried blood spot test (DBST) is needed. DBSTs have made screening for HCV infection much easier, and following appropriate training, does not require professionally qualified and clinically trained staff to conduct the test. Some services use the oral tests for service users who may not be regarded as a high risk for having HCV, for example those self-identifying as primary alcohol users.



## Questions for keyworkers/Practitioners and their managers

- Do staff have access to dried blood-spot testing (DBST) kit in the keyworker setting?
- Has sufficient time been allocated to discuss and undertake a test?
- Have staff been trained in how to have pre and post-test discussions?
- Are staff clear on how the offer is recorded on the National Drug Treatment Monitoring System (NDTMS) requirements?
- Are there service guidelines to support those discussions and do they reflect best practice from guidance such as NICE and PHE?
- Do these guidelines cover amongst other things consent (for testing, communication with GPs, referral to treatment services); how the test will be undertaken and results given?
- Are there patient information leaflets (PILs) which describe the above including treatment options including access and referral?
- What does “Ask regularly; Ask well” mean to your staff in terms of their own practice?

Keyworkers/  
Practitioners  
should regularly impart  
information and advice on HCV  
during encounters (planned or  
opportunistic) to service users; enquire  
about recent risk behaviours, and give  
information about the risks of infection and  
its effects; and help the service user understand  
the role of testing and treatment. Those at risk  
should be offered access to antibody screening  
testing and to PCR testing to confirm HCV infection.  
Testing should be repeated at least annually for  
those whose behaviour still puts them at risk. National  
guidance such as that produced by NICE, or regional  
guidance produced by, for example, commissioner and  
provider and ODN stakeholders with Public Health  
England (PHE) support, should be used to inform  
pathways to ensure best practice at all times.

*A guiding principle about testing for workers  
might simply be: “Ask regularly; ask  
well”.*

## Possible solutions

- Guidelines for pre and post-test discussion for Hepatitis B, C and HIV testing

### Issue

The successful micro-elimination of hepatitis C (HCV) can only happen through good partnership working. This is because micro-elimination efforts are a combined effort between a range of agencies across multiple intersecting pathways. These include drug and alcohol services, who can find patients with active HCV infection; NHS Acute Trusts, which house the HCV Operational Delivery Networks (ODNs), which themselves co-ordinate HCV treatment via Clinical Nurse Specialist teams; GP surgeries and primary care teams; and the peer organisations who can help link people into treatment, the most significant nationally being the Hepatitis C Trust. However, there are other agencies who can and do play critical roles which have been made even more significant during the pandemic. These have included the staff of temporary accommodation sites such as hotels and hostels, housing associations, shelters, Housing First, and rough sleeping initiatives.

One upside of the pandemic (if it can even be framed like that!) has been that many homeless people, or those with unstable accommodation, have been able to be temporarily housed for some months during different points of the pandemic waves. At the same time, testing rates have fallen dramatically in services nationally as footfall to services has declined, meaning by association that opportunities for face-to-face testing have declined. Necessity and opportunity have combined to drive local partnerships to come together and physically reach out to where service users have been relocated. Typically, outreach began in the hotels, with Covid-19 testing as the main initial focus but widening to incorporate HCV testing through 'pop-up events', and then more joined up treatment initiatives. 'Pop-up events' have come in different forms (run out of gazebos or clinical vans) and with different offers (testing only or with added-on treatment starting).

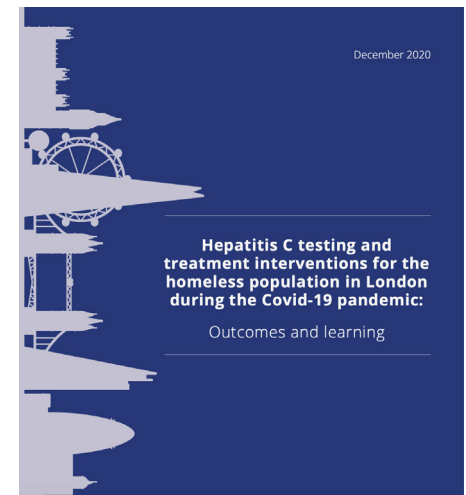


The field is seeing an increased emphasis on reducing health inequalities and meeting the needs of 'inclusion health' groups, which include people who inject drugs (PWID). Emerging Integrated Care Systems (ICSs) are increasingly using 'place based' commissioning approaches, and primary care will become the centre of a range of services for these groups. Consequently, there are opportunities to 'reboot' shared care for PWID, and to put blood-borne virus issues back on the shared care planning and treatment table between primary and secondary care.

A number of excellent reports have detailed the implementation and outcomes of the efforts of the last year, notably in London but also country-wide. One such is 'Hepatitis C testing and Treatment interventions

for the homeless population in London during the Covid-19 pandemic: Outcomes and learning' by the London Joint Working Group (December 2020),

available at <http://ljwg.org.uk/wp-content/uploads/2021/01/HCV-testing-in-temporary-accommodation-during-lockdown-December-2020.pdf>



### ORIGINAL

#### Evaluation of Hepatitis C Test and Treat Interventions Targeted at Homeless Populations (Outside London) in England During the COVID-19 Pandemic

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#### BACKGROUND

Hepatitis C virus (HCV) is a bloodborne viral infection of the liver that, if untreated, can cause cirrhosis, liver failure, and liver cancer. In 2019, Public Health England (PHE) estimated that 69,000 people are chronically infected with HCV in England, with many drawn from marginalized and underserved groups in society, such as people experiencing homelessness.<sup>1</sup>

In response to the global coronavirus disease 2019 (COVID-19) pandemic, national restrictions on movement

and social distancing were introduced in March 2020 and eased in July. During this time, there was disruption to many healthcare services, including testing and treating for blood-borne viruses, such as HCV. However, some English HCV care providers and allied stakeholders seized the opportunity to access homeless populations who were temporarily housed following government instruction<sup>2</sup> and so were less geographically dispersed and potentially more stable.

This article provides an evaluation of these test and treat HCV interventions for homeless people while they were

Abbreviations: Ab, antibody; COVID-19, coronavirus disease 2019; HCV, hepatitis C virus; NHS, National Health Service; PHE, Public Health England; PPE, personal protective equipment.  
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Another, which looked at efforts outside of London, is the 'Evaluation of national homeless outreach hepatitis C testing and treatment initiatives' by Public Health England (PHE), available at <https://aasldpubs.onlinelibrary.wiley.com/doi/10.1002/cld.1098>. There were some key lessons learnt from the evaluation which translate into potentially helpful questions for member Trusts.

## Questions for services undertaking partnership working and events

- Are there strong partnerships across multiple agencies in your locality?
- If so, are you an active member; if not, how can you be?
- Do you use and share existing local resources such as Standard Operating Procedures (SOPs), risk assessments, and information sharing templates?
- Do your Trust's Human Resources and procurement policies allow you to be flexible and innovative (e.g. examples of services who had gone out and bought a gazebo for 'pop up' events)? If not, how can your service begin a negotiation within your Trust?
- How can you promote testing interventions using appropriate content and language to avoid stigma? If not you, who are the local agencies and groups who understand your target audience, and how can you work with them?
- Have you got access to incentives for you partnership events? How will you monitor their effectiveness
- Will you adopt a whole health approach, such as screening for other diseases at the same time as undertaking a HCV partnership event?
- How will you monitor and evaluate your partnership efforts?
- Is there an opportunity to share resources across the partnerships and ODNs?

### Exemplars

- [Monitoring and evaluation of hepatitis C initiatives - GOV.UK](https://www.gov.uk/government/news/monitoring-and-evaluation-of-hepatitis-c-initiatives) ([www.gov.uk](https://www.gov.uk))
- Nottingham Shared Care antibody testing (see resources)

## Issue

Hepatitis C (HCV) treatment is now unrestricted, and active use of substances is no longer a barrier. However, service users should be supported to minimise their alcohol use and all people who inject drugs (PWID) should be provided with adequate needle exchange equipment.

Since 2016, the treatment landscape changed dramatically with the phasing out of combination therapy (Interferon and Ribavirin). This treatment was not well tolerated with many unpleasant side effects. It comprised of a weekly injection and daily tablets for 24-48 weeks with a 45-85% chance of being successful. Pre-treatment tests were also invasive and consisted of numerous blood tests and a liver biopsy.

The great news is that now the treatment for HCV is simply one Direct Acting Antiviral (DAA) tablet taken orally for 8-16 weeks with around 98% success rates. Pre-treatment tests are still carried out by blood test, although less blood is required and poor venous access is also no longer a barrier. This is because treatment can be accessed where venous access is not possible on the basis of an PCR+ result gained through dried blood spot testing (DBST) or Cepheid machine testing. The liver assessment is now done by a fibroscan which is non-invasive and similar to an ultrasound.

Every opportunity should be taken to educate service users around the new treatment as myths still exist and services users are refusing treatment based on out of date information.

Treatment regimens are decided by Acute Trust hepatology teams based on clinical information and genotypes. Typically, in this country, there are 4 genotypes with some subsets, and the only relevance now is the treatment regime that may be used.

In 2016 NHS England (NHSE) developed twenty-two Operational Delivery Networks (ODNs) each with a Clinical Lead, a main 'hub' hospital and several 'spoke' hospitals. Each ODN works together to deliver HCV treatment according to the NHS Elimination Tender procurement arrangements. Currently under this agreement there are three Pharmaceutical companies that are supplying treatment, namely Gilead, MSD and AbbVie. The NHSE procurement arrangement gave them an allocated market share, which promoted collaboration rather than competition. As part of this 'new deal', there was an expectation that each hospital would undertake outreach clinics, and the 'gold standard' was for each addiction treatment service to have an onsite hepatology clinic. This involves a hepatology clinical nurse specialist and/or a hepatology/infectious diseases consultant who will come to the service to provide HCV treatment to patients onsite. Experience suggests that this works best when the service has a named person/s who are responsible for coordinating the clinics, and peers are actively involved in supporting service users to attend, and involved in other engagement activities.

## Possible solutions

- [Community Peer Programme | Hepatitis C Trust](https://hepctrust.org.uk) (hepctrust.org.uk)
- Comparing data held at DTS with data at ODNs

## Questions for keyworkers/practioners and their managers

- What is your referral pathway for anyone who is HCV PCR+?
- Do you have an onsite clinic?
- What level of knowledge do your teams and service users have about 'old and 'new' HCV treatments?
- How are treatment outcomes monitored?
- Are staff clear on how this is recorded on NDTMS?
- Are there service guidelines to support those discussions and do they reflect best practice from guidance such as NICE and PHE?
- Do these guidelines cover amongst other things consent (for testing, communication with GPs, referral to treatment services; how the test will be undertaken and results given)?
- Are there patient information leaflets (PILs) which describe the above including treatment options including access and referral?



Consider the stages/setting in the document we have presented thus far as a roadmap of a journey. As with any journey, the state of the road surface can help or hinder our travel, and how easily or quickly we arrive at our destination. In the journey towards hepatitis C (HCV) elimination which we have described, pieces of data are like the 'cats eyes' embedded in the tarmac, guiding our route.

When thinking about data we have three things to consider:

- What data do we have and record?
- What data do we need to record/share?
- How do we use the data?

At each stage in the roadmap we will be faced with asking these question.

## **What data do we have and record?**

It might be that in a given stage in a service user's journey, we record a lot or a little amount. Is it for the benefit of the service user, a policy and procedure requirement, or an organisational or external reporting requirement?

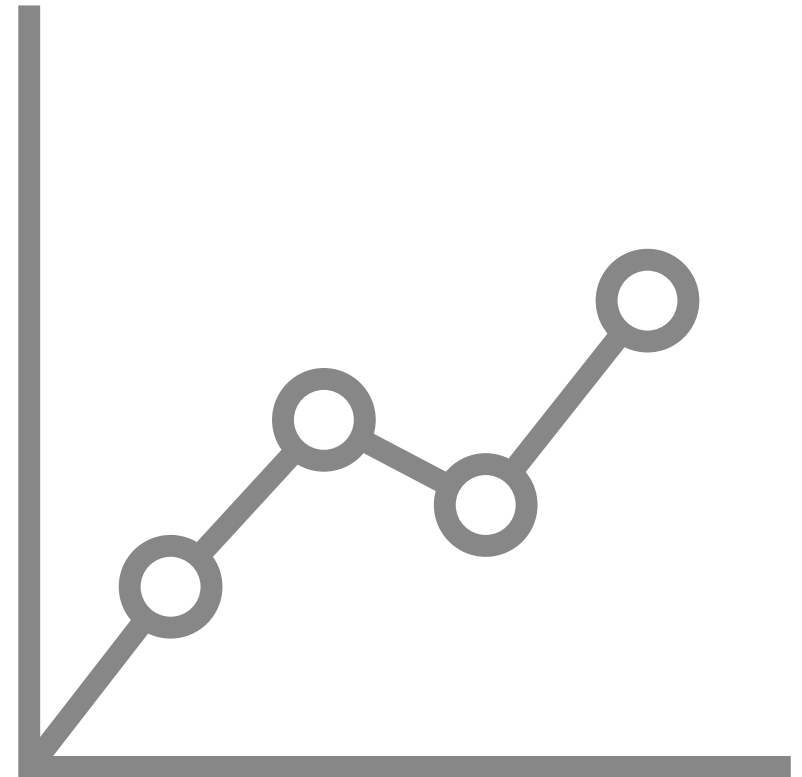
Is the data entered onto an electronic management system or is it recorded in some other way, electronically or on paper? The way data is recorded has implications on who can share data, and how easy it is to do that with others.

The data we can get out of a system is only as good as the data entered. How do staff enter data into the system; have they got the necessary equipment; and training to use the system? Do they know how to codify the data? Do they know how to use the NDTMS coding system? Do staff know why they are asked to record data in the way they are? Do staff have protected time to process the data?

### What data do we need and share?

Data which supports treatment is most useful when it is shared. What data we need, and who needs it, defines the reasons why we collect data. Things to consider are:

- What data do you need at that stage of a client journey and how do you get it?
- Is the information available and can it be easily shared?
- How do you store the information?
- Are the systems used to record the data 'fit for purpose'? Do you need to look at modifying the recording system, or implementing a new recording system and methodology?
- Is the information internal to the organisation or from an external source?
- Are the correct information governance and data sharing agreements in place?
- How is the data shared? Is supported by a clear and understood Data Privacy Impact Assessment (DPIA)?
- Do staff know how to record and process the shared data?

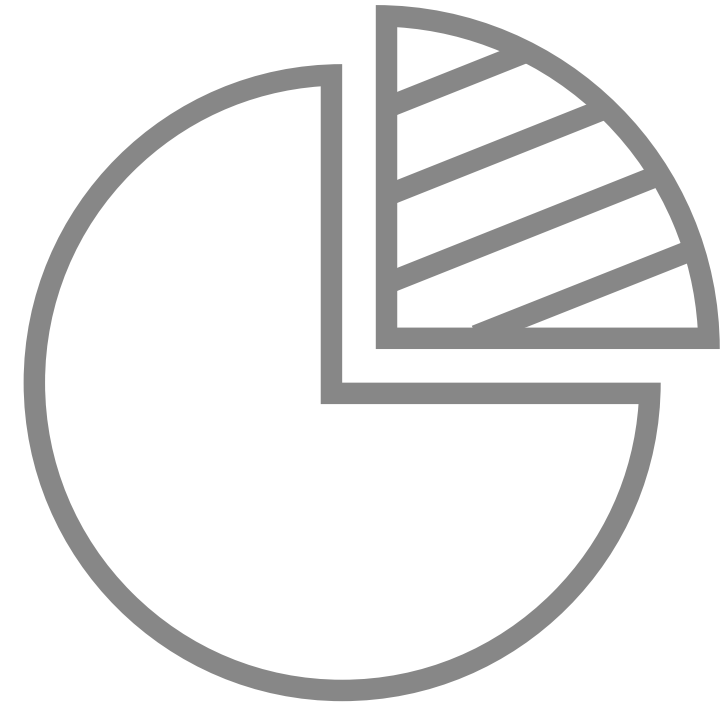




### How do we use data?

We need our data to be illuminative, like 'cats eyes' in the road. Things to consider here are:

- Are all the 'cats eyes' there, that is: have you got all the pieces of data you need?
- Do they work, that is: is your data good? Is it of high quality?
- Do you understand and believe what the data is telling you? Is it accurate?
- What processes do you have in place to improve data quality?
- How are you going to use the data? Will it trigger a specific action? Will it be used in reviewing your service model? Will it be used for external reporting?



### Useful links

NDTMS Links

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/873096/PBBV\\_guidance\\_NDTMS\\_core\\_dataset.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/873096/PBBV_guidance_NDTMS_core_dataset.pdf)

<https://www.gov.uk/government/publications/recording-data-about-blood-borne-virus-interventions>



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